

Pursuing the adoption pathway: the lived experiences of people living with HIV

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Abstract

Pursuing the adoption pathway: The lived experiences of people living with HIV

This exploratory study of 7 participants including individuals and couples, examined the challenges that people with HIV faced as they navigated through the intricate processes of trying to access adoption services in the south of England. In this Interpretative Phenomenological Analysis (IPA) study, some participants described positive experiences with social workers. However, this was in the minority. Lack of information, inadequate support, stigma and discrimination, cultural insensitivity and disempowerment were frequently reported experiences of participants. Greater understanding and better education for social workers would enhance adoption assessment frameworks to improve access to adoption by people with HIV.

Key words: adoption, HIV, lived experiences, interpretative phenomenology, social worker.

Introduction

Since 2012, the United Kingdom (UK) government has emphasised the importance of improving efficiency in adoption processes and improving the value and quality of children's lives with their adoptive families. The Children's Act 1989 made it clear that adoption is a serious decision made from assessments and evidence used to ensure that the child's welfare will be safeguarded. The current discourse on adoption suggests that prospective adopters should not be rejected at the point of initial enquiry purely from their background or health issues. There is a need to reduce barriers and discrimination that prevent potentially good, caring adoptive parents from adopting.

Thus, people living with HIV (PLWHIV) should be considered equally where health matters are concerned and with regard to their rights to achieve parenthood. However, Paiva et al. (2003) showed that in a sample of 250 HIV-positive men between the reproductive age of 17 and 74 years, 92% of them were on antiretroviral treatment, stable and well. All participants were asked if they had a desire to have children. Out of 250 men, 43% (107 men) wanted children. Of these 107 men, 26% wanted a baby, yet 4% had a desire to adopt. On the contrary, 52% of the 250 men had expressed no desire to have children due to fear of horizontal transmission and professional or societal stigma, only 4% (5) opted for adoption. Many studies suggest that some PLWHIV do not feel encouraged by professionals to adopt children. Structural barriers within adoption systems, lack of information or support, ignorance, stigma and discrimination associated with HIV all acted as barriers for PLWHIV seeking to adopt children (Chipawe Cane, 2017; Underhill, Kennedy, Lewis, Ross & Loutfy, 2016).

Nattabi, Thompson, Orach and Earnest (2012) noted that many PLWHIV felt stigmatised by health and social care workers who criticised them for wanting children. Due to judgemental attitudes and lack of information, the needs of PLWHIV have not been fully addressed. Moreover, anxieties around the prevalence of HIV may increase concerns by health and social care professionals of whether parents with HIV could provide stability to children because HIV has been seen to contribute to children experiencing stigma, discrimination and psychological burden. Because of concerns that parental chronic health conditions tend to affect children's quality of life Gardino, Russell and Woodruff (2010) concluded that ongoing discrimination often existed in the adoption process, resulting in many PLWHIV being unfairly disadvantaged. However, if social barriers are removed, this may create opportunities for PLWHIV to adopt (Underhill et al., 2016). This paper, therefore, reports from an exploratory study on the experiences of people living with HIV on their journey to becoming adoptive parents through the adoption system in the south of England. In the next section, we present an overview of the screening and adoption processes in the UK.

The process of adoption

Adoption processes in the UK are outlined in the Adoption Agencies Regulations 2005 (amended 2011), Adoption Statutory Guidance (2013), the Adoption National Minimum Standards 2014 (Department of Health 2014), and other relevant legislation, regulations and guidance. The assessment process of adoptive parents involves stages one and two. The pre-stage one process, however, encourages those interested in adoption to approach adoption gateways for information and guidance. Issues around infertility, fertility treatment, age, bereavement and loss are explored in order to assess eligibility. Through adoption information sessions or a social work home visit, prospective adopters may express an interest to adopt. This stage is criticised for its subjective nature because applications that are

not deemed viable can be rejected (Gardino et al., 2010; Moodley et al., 2014). Thus, the extent to which HIV is accepted is unclear.

The first stage is the screening stage that runs for two months and involves adoption social workers gathering information about prospective adopters, undertaking an evaluation of background investigations with many agencies, such as conducting police checks and health checks, as well as reference enquiries. Ultimately, social workers provide adoption preparation training, assess parenting capacity, parenting skills and provide prospective adopters with information about available children. Stage two involves an allocated social worker processing assessments, Adoption Panel scrutiny and the Adoption Agency Decision-maker who makes the final decision as to whether or not prospective adopters are suitable to adopt. Upon successful stage two assessments, potential adopters are approved; consequently, matching of adoptive parents to children requiring families begins. Gerrand and Nathane-Taulela (2015) and Underhill et al. (2016) however, report that adoption assessments can be complex where HIV management is concerned. They suggest that social and structural complexities lead to HIV-positive applicants withdrawing from adoption assessments to avoid either medical screening, further HIV testing, invasive assessments or discriminatory and unacceptable attitudes portrayed by professionals. Their studies advocate for adoption structures that are sensitive to HIV.

Literature review

Despite the extensive literature on adoption and in particular by minority groups, there is a dearth of studies dealing specifically with PLWHIV trying for adoption. Specifically concerning PLWHIV, this review presents the literature under three main themes: *The Right to Adopt*, *Health Considerations of Potential Adopters*, and *Ethical Dimensions*.

The right to adopt

The rights to adoption for PLWHIV seeking to achieve parenthood lie in the Human Rights Act (1998) asserting the right of all individuals to have a family. Indeed, this right should be considered in line with the Paramountcy Principle. This principle states that the child's welfare is paramount. Thus, adoptive parents should be best suited to meet the needs of that child. The literature on PLWHIV and adoption is limited, although legislation continues to discourage discrimination against health matters such as HIV. There is evidence to suggest that some PLWHIV feel discouragement by professionals from adopting children. Moodley, Cooper, Mantell and Stern (2014) report a lack of sufficient information about adoption and that this prevented PLWHIV from receiving adequate support.

Health consideration of potential adopters

The assessment process requires applicants to demonstrate that they are physically, emotionally and psychologically healthy enough to commit to bringing up a child. The Department of Health (2003) requires assessors and agencies to be satisfied that prospective adopters will continue to enjoy good health when they take up adoptive parenting responsibilities. Undertaking full medical checks and looking at adoptive parents' medical histories are part of the screening process and decisions about adoptive parents' health suitability carry a good deal of weight in the adoption process. Although the adoption minimum standards (Department of Health, 2014) clearly states that mild chronic conditions are unlikely to affect the adoption process, it also emphasises that serious health issues may impact on adoption chances if illnesses prevent children from being offered a full range of opportunities that promote their development (Douglas & Philpot, 2003).

Uncertainty about HIV related mental health illness and its impact on parenting capacity may result in professionals feeling reluctant to accept people at risk of these issues. This disadvantages many PLWHIV and potential adopters may become subject to extensive scrutiny beyond the ordinary process and may become marginalised when seeking adoption because of professional anxieties and a lack of current HIV-related knowledge by health and social care workers (Gardino et al., 2010). Contextually, in a population of PLWHIV, about 25–40% may have fertility difficulties (Kushnir & Lewis, 2012), and some are likely to apply for adoption. Therefore, adoption systems need to demonstrate a sensitive approach towards those PLWHIV entering the adoption system. Thus, the adoption minimum standards suggest that it is the duty of local authorities to welcome, value and support prospective adopters, and assess them on their ability to meet the unique needs of a child and any ethical questions about HIV and adoption need to be considered (Department of Education, 2014).

Ethical dimensions

The National Institute for Clinical Excellence (NICE, 2013) guidelines for HIV treatments acknowledge that there is a need to promote the rights of PLWHIV to have children. Health risks for adopted children are minimal as there are no risks for vertical transmission of HIV. While PLWHIV are likely to offer relatively risk-free home environments, some may need adoption counselling, emotional preparation for adoption, post adoption advice and guidance on long-term disease management. Thus, the provision of adoptive parenthood requires balancing adoption rights, moral, welfare and best interests obligations to ensure long-term stability for prospective adoptive parents without making unjustified judgements (Clifford & Burke, 2004).

How this study fits with existing literature

Despite the rights of PLWHIV to adopt and adoption policy guidelines that promote inclusive adoption assessment procedures, there are limited empirical studies in the UK exploring the experiences of PLWHIV going through adoption. A qualitative study by Underhill et al. (2016) with 77 professionals and service providers assessing PLWHIV for adoption concluded that structural barriers, lack of awareness and stigma could be factors prohibiting PLWHIV from adopting. However, it is not clear from the perspective of PLWHIV what obstacles they faced when going through the adoption processes. This exploratory study was designed to highlight the experiences that prospective adoptive parents living with HIV face, when seeking to adopt a child through the UK adoption systems. This study will add to adoption research by providing insight into the experiences of PLWHIV who have accessed adoption. It will also strengthen overall published literature around HIV prevention.

The study

This study was an original study that examined the experiences of PLWHIV who went through the adoption process for child adoption, using an exploratory IPA approach. The thesis supporting this study is framed within the view that HIV is now a long-term condition and that those seeking to adopt should be allowed to experience an adoptive experience without feeling marginalised. The study, therefore, was interested in illuminating the lived experience of PLWHIV through the adoption process. The study only focuses on access to formal UK adoption services in England, and does not consider international arrangements as they vary by country.

The research question

Main question: How do PLWHIV perceive their experiences through the process of applying to become an adoptive parent?

Subsidiary questions: What are the challenges and joys faced by PLWHIV going the adoption assessments?

Theoretical framework

Risk and resilience theory and IPA

The risk and resilience theory (Masten & Powell, 2003) provides a theoretical framework for understanding how PLWHIV who wish to have children identify risks of transmission and process these to prevent horizontal and vertical transmission. Resiliency is a process of active adaptation when responding to, or surviving threats, adversity or risk factors. In this study, adversity is associated with the loss of ability to have a child due to threats of HIV transmission. The process of resilience calls for one to feel that they can cope with the process of challenging threatening life events (Masten & Powell, 2003). The risk and resilience framework helps identify internal resilience and informal sources of support from social networks that increase resilience among PLWHIV (van Eeden-Moorefield, 2008). Attributes that connected to psychological theories closely relate to the IPA framework (Smith, 2004) supporting analysis that draws on psychological processes.

Method

Study design

This research followed the Interpretative Phenomenological Analysis (Smith, 2004). Through exploration, we sought to understand in detail, participants' personal inner worlds as they tried to make sense of their adoption experiences. We explored associated feelings by looking in-depth into participants' narratives (Smith & Osborn, 2007). IPA is underpinned by hermeneutics phenomenology elucidating that individual experiences are influenced by

social, cultural, historical elements, language and emotions encountered while going through life events and how people make sense of those experiences (Eatough & Smith, 2006). Thus, we wanted to identify how participants felt and what they thought about going through adoption while living with HIV.

Double hermeneutic meaning-making occurred (Smith, 2004), helping us capture how participants made sense of their personal and social world. Thus, meaning was constructed from the interpretative interaction between the main investigator (TC) and participants through a reflexive in-depth process of understanding how participants made sense of their lifeworlds. The researchers had previous experience of working with PLWHIV as a social worker (TC) and a health visitor (VV) in the wider communities. Thus, the researchers' knowledge and awareness of issues around HIV and health and social care issues were important in understanding and interpreting participants' experiences. This enabled an investigation of personal accounts to be conducted with clarity and with trustworthiness ensured (Smith, 2007). Thus, IPA was adequate because it allowed joint reflections between all researchers using analytic account (Smith & Osborn, 2007).

Recruitment and sampling

Ethical approval from the University of Surrey ethics committee was received as it was part of a doctoral research project. The lead researcher (TC) also received an honorary research status from the Terrence Higgins Trust (a charitable organisation supporting PLWHIV), which acted as the hub for recruitment. This promoted the legitimacy and confidence about the research and its intentions. Recruiting from HIV charities sought to render neutrality, promote anonymity, reduce anxieties about adoption applications that were underway and to facilitate data accessibility with the use of private HIV online forums and support groups.

This also enabled identifying eligible participants before they were invited to participate (van Eeden-Moorefield et al., 2008). Thus, purposive sampling techniques were utilised to recruit those willing to participate (Smith & Osborn, 2007; Brocki & Wearden, 2007). Chain-referrals enabled accessing hard-to-reach individuals. The study recruited PLWHIV who were in their reproductive age and either in a sero-discordant or sero-concordant relationship, and who had accessed or were in the process of accessing adoption services in England.

Participants

The study used an acceptable sample size for IPA as recommended by Smith (2007). IPA supports small sample sizes to facilitate in-depth dynamic, reflective interpretative analysis of the rich data that emerges from interviews (Brocki & Wearden, 2007). Out of 18 respondents who expressed interest in the research, 6 participants had only attempted fertility treatment (and of these, 4 had explored adoption but not commenced the process), 1 participant became unwell and withdrew, and 4 participants dropped out.

Due to attrition and eligibility, the study subsequently relied on five semi-structured interviews involving 7 participants in total. These participants comprised 2 heterosexual white couples with HIV-sero-discordant status (both these couples were working class); 1 heterosexual couple with HIV-sero-concordant status (both HIV positive, middle class); and 2 individual men whose sexual orientation was homosexual (1 participant working class and the other a middle-class man with a senior management job in the education sector). Of these, only one single man was unsuccessful in adopting a child. The sample was homogeneous in that all participants were experiencing HIV-related infertility and they had sought child adoption services in England. All participants were above the reproductive age and within the required age to adopt a child. The sample size allowed a close exploration of the participants'

lifeworlds, thus keeping the research very close to individuals' personal experiences and perceptions, in a better and much more attentive fashion than a larger sample would have allowed (Smith & Osborne, 2007; Flowers, Davis, Larkin, Church & Marriot, 2011). The demographics of participants are presented in Table 1.

insert Table 1: here

Data collection

Face-to-face interviews were conducted by the main investigator (TC) at a venue that was comfortable for participants, for example, at their home or in a private meeting room at a charity, the Terrence Higgins Trust offices. Interviews lasted between 45 minutes and 90 minutes depending on the complexity of participants' narratives. A loosely structured interview schedule guided the interviews with participants. All participants provided consent to audio-record interviews and supported the study. Couples were interviewed together.

Data analysis

All interviews were transcribed, and following IPA's analytic process, interviews were first transcribed, then read and re-read making free-text writing. Interview transcripts were individually and rigorously analysed within an ideographic case analysis to create themes and clusters but also to maintain individuality (Smith & Osborn, 2007). In each case analysis, themes were determined. They were recorded to reflect original words that were relayed by participants. This was useful for interpretation. A cross-case analysis was further undertaken for divergence and convergence of themes to create a shared understanding of a holistic analysis of each ideographic case and noting individual differences. Through mapping of themes in a cross-case analysis, master themes were created. These reflected a shared

understanding arising from the experiences of participants as a group. Through monthly meetings between the three researchers (TC, VV and WK), analysing and making connections between collective superordinate themes, sub-themes emerged, with the restructuring of themes necessary until final themes provided holistic sense-making (Flowers et al., 2011; Brocki & Wearden, 2007). Final themes to report upon were agreed after detailed checks and a process of an inter-rater reliability examination (VV and WK).

Four themes were identified and these are presented below with anonymity of all participants protected. All names used here are pseudonyms:

1. *Barriers: Knocking on doors with no answer*
2. *Hopelessness: 'You are actually being judged, not assessed for adoption'*
3. *Difficult staff: Social workers' lack of knowledge and sense of fear*
4. *Unbridled joy: The reality of becoming an adoptive parent*

The themes describe the uniqueness of the lived experiences of people living with HIV trying to access adoption services. The first theme starts off with the initial experiences of hitting your head against a brick wall and being faced with such incredible reactions that adoption would be futile due to their diagnosis. A state of hopelessness ensues in the second theme illustrating how participants felt negatively judged for being HIV positive rather than being assessed for being an adoptive parent. These reactions were further complicated by social workers' lack of knowledge and understanding of people living with HIV. Finally, the last theme highlights the sheer joy and exultation of those who succeeded in becoming adoptive parents.

Findings

1. Barriers: Knocking on doors with no answer

Participants engaged and endured through what appeared to be adoption procedures that were complex to break through. A number of sub-themes were identified such as inaccessible services, stigma and discrimination. Thus, the theme *Barriers: Knocking on doors with no answer* reflects the battle to achieve a social status of parenthood.

For Gary, commencing the process of applying to become an adoptive parent was difficult due to the lack of information and resources:

No one gave me information. The process is not an easy one. It is not as easy as ABC. You don't know where to start, you don't know who to go to, and you don't know who to contact or talk to. When I saw the advert from XXX, I decided to contact them. I spoke to a man. He did not give me any other advice. I called again, and another person gave me the details of another team. They referred me to an open event, but when I went there, they were not very helpful. [Gary]

Gary identified challenges centred on access to information. His experience alludes to the lack of information, support and guidance as barriers to instigating the adoption process. Others like Hillary and Gabrielle report making enquiries but receiving no response:

Right from the beginning, I rang XXX and XXX Local Authority, and I could not get hold of them. I sent emails explaining my situation asking to make an application to

adopt, but no one returned my emails. They were a terrible adoption service. They did not return my emails or my telephone calls. [Hillary]

The social worker asked us if we wanted some help with understanding adoption and how it works. She said she would give us information about adoption preparatory training programmes, but no one got back to us. It was very unpleasant; they could have communicated better. [Gabrielle]

Poor responses from agencies and lack of communication about various methods that facilitate the adoption process contributed to additional barriers preventing participants from accessing or navigating through adoption services. The lack of communication by adoption staff/teams was associated with incompetence:

They just didn't communicate. I think it's just a lack of competence; it's not just my experience, it's people from XXX, and from work who say it. It becomes a joke. It should actually not be a joke; it's quite serious ... I can't understand why. [Alan]

Poor communication was associated with insensitive practice and lack of competence around interpersonal skills. It would appear that better relational skills were anticipated.

Additionally, others thought that challenges around access to adoption were associated with HIV disclosure. For example:

I told them everything. I disclosed everything about our circumstances. We thought it is better to be upfront from the beginning. But, no, I was not very impressed. They

never got back to me ... It was an appalling adoption service. In this day and age, you would not think that there is still such negative attitudes about HIV. [Hillary]

They asked about my health. I said, be my guest. I told them about my HIV and my mental health. After that, no one got back to me. [Gary]

The above excerpts represent a willingness to be open and transparent about one's sero-status when seeking to adopt. Hillary and Gary thought that, by disclosing that they were HIV positive from the beginning, they would be respected for being open and honest, thus enhancing their chances to be considered. However, from their perspective, when they disclosed, they were not offered further opportunities to access information, advice or support. Thus disclosure resulted in a state of being stigmatised and a feeling of hopelessness.

2. Hopelessness: 'You are actually being judged, not assessed for adoption'

HIV disclosure was considered a prerequisite in the adoption process but a difficult thing to undertake, with participants showing a level of fear. Fear of disclosure was associated with internalised stigma, anxieties and doubts about possible discriminatory practices. The central thread within this theme is the notion that, following disclosure, participants were being constantly judged for being HIV positive and not being adequately assessed for their competency for parenthood. Common experiences are typified below:

I was really nervous. I was concerned about stigma because we came across this with social services. We had heard people talk about this in the support group. I was concerned about stigma. Actually, very quickly it became quite apparent they were

not interested. There was nothing I could have done, but I just had to continue trying.

[Alan]

It is not easy to disclose. When you disclose you hope to be treated fairly with the illness. From the beginning, each time we emailed or telephoned a local authority, we told them about the HIV. It's better than doing it at a later stage. At least they will know that fact from the beginning ... When you disclose, it seems they think you are not fit to look after a child or something. [Hillary]

Worry about reliving negative attitudes and HIV-related social stigma are evident here and these influenced disclosures with hope to be accepted in the system. However, fear of professional prejudice reportedly became a reality that was interpreted as a lack of interest.

The adoption assessment process was perceived as unnatural and biased because decisions were made following a short interview process:

This woman who had met me for only 90 minutes, judged aspects of my life. Because I spent a lot of time with my grandfather and had regular contact with my father, she ... said that there had been no emotional connection between us. They say you are being assessed, but you are actually being judged. I think they are making judgements about you, from there and that point on. I think any adopter feels that. That's how it is.

[Alan]

Alan suggests that adoption assessments may involve prejudices and subjective judgements. Sometimes, the interviewing process involved a construction of misconceptions that resulted

in unfavourable conclusions that undermine the life experience of a prospective adopter and ultimately one's adoption assessment. For Gary, judgemental attitudes commenced at the initial contact with adoption teams:

You ring for the first time, you go for the information evening, and you have your initial meeting with the social worker. You talk about HIV. From that point, you are being judged. I said that's fine, but you are making a judgement on HIV, not on anything else. I said you are in no position to make that judgement. That is your own ignorance. [Gary]

Gary rationalises that focusing on HIV could result in prejudice and missing a holistic and true picture of potential adopters' capabilities. For Hillary, social work training does not appear to eliminate prejudice:

I have been shocked by the attitude and prejudices that social workers have against HIV-positive people. It's appalling, it really is. No matter how much training you do as social workers, people still have prejudices and feelings. You know, people with HIV will always feel this. [Hillary]

It seems those applying for adoption felt that social workers were making a judgement about their HIV and not their ability to adopt, to parent children, or their ability to provide a safe and loving environment for a child. Participants were vague about whether social workers were certain that HIV had an impact on their ability to adopt or parent children. They wanted social workers to appreciate their strengths as individuals:

I have the knowledge. I have the know-how. I want to change things for the better. I am a very placid person. I am in control of the situation. I am a fighter. The discrimination I am going through is just not good. It is the children who suffer at the end of the day. [Gary]

Further negative views were reported about sexual orientation:

The agency that I first approached this year was like because you are a ... (sigh ... deep breaths) single gay male, we don't think you have the emotional intelligence or the network to adopt a child. They forget who you are. [Alan]

The above demonstrates stereotypical judgements based on sexual orientation and heterosexism. Alan was trying to adopt as a single homosexual male and a middle-class professional with a stable job. He refers to his professional status, as a head teacher when he pronounced a concern around how social workers may forget 'who you are'. It appears that premature judgements and multiple discrimination (HIV and/or sexual orientation) were perceived as the cause to decline an application to become an adoptive parent. HIV and homosexuality, for Alan, resulted in double stigma and double discrimination. Participants felt a sense of misjudgement, helplessness, and being undervalued due to a lack of knowledge of HIV.

3. Difficult staff: Social workers' lack of knowledge and sense of fear

Some participants reported that social workers attempted to sway them from the adoption process:

When we told them about the HIV, they did not say directly we could not adopt, they said to me, yes, you can adopt, but it will not be very easy, so you need to contact us. That was it. I contacted them, but they never responded. [Hillary]

The excerpt above depicts discouragement and what was construed as indirect discrimination from pursuing adoption. Paradoxically, disclosure was seen as a barrier as opposed to a gateway for trust and opportunity:

I was really offended by the letter they wrote to me when they looked at my application. The key issues in the letter were: you might not live longer to have a child; basically, that's what it was saying. I was like, how can you say that. You have not contacted my HIV consultant or my GP. How can you say that? I was absolutely angry. [Alan]

Alan's experiences depict negative stereotypes and judgements arising from social workers, seemingly created before any formal investigations, or health assessments were undertaken to confirm any diagnosis and prognosis.

Hillary felt a sense of forced helplessness:

It felt like no one was seeing him as an individual. They didn't even see us as a couple, and my status [negative] didn't matter but his HIV status. They didn't take into account why we applied for adoption in the first place, all they could see is HIV. Because of the disclosure, they simply think there is no need for further medical checks and not even to consult me, yet we could have taken a chance to have our own

baby if we wanted to. It's just wrong. [Hillary and Marius]

The absence of consultation with medical professionals, usually dominant within the realms of inter-professional working within the adoption process, suggests a level of bias and judgemental practices that are potentially associated with discriminatory practice. From the above excerpts, disclosure may not prevent gatekeeping, stigmatising attitudes or resistance to accept PLWHIV within the adoption system for sero-discordant couples.

It was apparent that a lack of professional experience came in the way of sensitive practice. A typical example is drawn from Gabriella and Bred:

Especially at the hands of a newly qualified staff, a twenty-five-year old social worker who was himself new to adoption services, whose only qualifications were basic level, it becomes very difficult to change the mind-set of young people who may not have experience with HIV and with no real life experience of snubbing [humiliation or degradation]. [Gabriella and Bred]

From this, a relationship between inexperience and incompetence is suggested. There is an inference that, for social workers to understand discrimination, they need to go through experiences of being humiliated in their personal life.

It appears that risk aversion was associated with discriminating against with fear of making mistakes, as illustrated below:

What I was told was that they sat on the fence and they would not advise one way or the other. I think this is generally true for doctors, but maybe I'm wrong. They are

very risk averse are they not? They will not put anything in black and white unless they are sure they can back it up. [Alan]

I think they were just over-cautious, that is the problem, and this leads to many people feeling prejudiced against especially when they are not clear of the ins and outs of HIV. [Hillary and Marius]

Moreover, over-cautiousness or inconclusive decisions by social workers led to some participants feeling discriminated against:

Social Services rang me up, and they said, based on their medical advisor, we are not clear on what your life prognosis is. Therefore, we are finding it very difficult to decide whether we should go forward or not. I could not accept that the medical advisor for the panel could not make the decision one way or the other. They just sat on the fence. In the end, I could not go through with the adoption. [Alan]

Furthermore, when Hillary and Marius expressed an interest in adopting a child, their interest was declined. Hillary and Marius noted a disparity between the views of health professionals acting for adoption systems and those of specialist HIV consultants. A typical example is drawn from Hillary:

They refused to accept our request for an assessment, and they did not give us the reason for this. When we challenged them, they said, this has nothing to do with HIV. I was like, why are you saying you are concerned about whether adoptive children

may be affected long term by Marius' health [HIV+] if it has nothing to do with HIV (laugh)? You know what I mean (emphasis). [Hillary and Marius]

These suggest that the disparities between specialist HIV opinions and adoption medical advisors are likely to heighten anxieties and uncertainties regarding the adoption process because of potential discrimination that occurs due to inconsistency and the absence of a shared understanding or fear of moral hazards (placing children for adoption with those morally seen as unsuitable). This relates to HIV-related cautionary practice and reductionism by disconnecting HIV from the body of PLWHIV, even though the reality is that the body and the HIV are inseparable.

When faced with stigma and discrimination that prevented them from accessing adoption services, some participants started looking for adoption services outside their geographical location of residence. A typical representation of this experience is suggested here:

When I started the process, they told me they could not continue with my assessment. I was thinking I have spent 6 months already. So now, I have to do it all over again. So I started the process all over again with another agency. I had to fight my way through it again, they assessed me in the end. [Alan]

Frustration and despair associated with repeated efforts of contacting adoption services, undergoing screening procedures and being rejected are noted in the above extract. Although this maximised hope and chances to adopt, social workers were seen as powerful agents:

The trouble is that if you want to adopt, the power is in the social workers' hands.

[Hillary]

In that regard, Gary felt, if one fails to fight for what they believe in, that would only be an instrument for prolonged pain and suffering:

Adoption is a process that ummh, (silence) that is not inclusive. It does not welcome people in circumstances such as mine. They say that's what they want to do, but it doesn't. The pain I experienced through HIV, the mental health, the anguish and traumas I experienced were too much for me. It was like putting the iron on the fire to sort of reshape and make it a shape you want to make it. I am a fighter, so I will continue fighting until I have a child. [Gary]

Recounting historical traumas, for Gary, reaffirmed resilience, recreating self-identity, social identity and a sense of control over HIV-related marginalisation. To regain a sense of purpose, fighting was associated with challenging and making formal complaints about negative adoption decisions:

We have told them [Local Authority] a few times that we don't think that is right that they ignore us on and after we disclosed HIV. We had to challenge them. [Hillary and Marius]

Challenging discrimination implied seeking fair consideration and to be heard.

4 Unbridled joy: The reality of becoming an adoptive parent

This section explores feelings that relate to participants who had successfully adopted children. Participants articulated the difference between adoptive parenting and biological parenting. Alan found it ‘abstract’ to be an approved adoptive parent when his adoptive son was not yet physically placed in his care. The matching was already completed and the adoption order agreed, but Alan was waiting for the transition plan to commence:

It is funny really. I think it is hard for adoption to be real when it is like this. You are not pregnant. It is part of child development is it not? When a woman is pregnant and having a baby, it is true that there is a physical presence that you don't have. It is, it is really weird because, you don't have, and there is nothing physical. There are no scans, so it becomes abstract again. You get all these moments, all these pikes and spikes of concrete, kind of, wow, this is really happening and all of a sudden aww, nothing, nothing is really happening, you know (frustration, helplessness). [Alan]

The absence of carrying a pregnancy and experiencing labour implied that adoption is unnatural given the absence of the physical closeness with the foetus that is embodied during pregnancy. However, waiting for the adopted child to be placed in his care was emotionally challenging:

It is emotionally challenging because, this whole issue of being a single parent anyway, and you think what that entails really. My anxieties are around his disability. He needs a routine. He has already had a number of foster carers. With another change of parents and coming to a new house, he will find it difficult to express his emotions. For me, it is the whole idea of getting him settled, he may be challenging,

but I don't know. The exciting bit is building that relationship. That is the bit that you want isn't it? [Alan]

Alan's account represents mixed feelings associated with the evolution of adoptive families. The desire to form positive relationships with his child; to ensure emotional and behavioural development is framed, but fear of how the child's development would turn out was linked with the child's unstable foster care arrangements and pre-existing childhood experiences. The successes of adopting as a gay man were celebrated:

The joy is quite immense despite difficulties; it is absolute because gay men have fought for it, haven't they? All the generations, they have fought for equal rights in terms of homosexuality; and age of consent. There are a lot of things that have gone on. [Alan]

Alan rationalises the ideological difficulties linked to homosexual parenthood but celebrates the benefits of fair treatment without prejudice within the adoption system.

Hillary and Marius, as well as Jenny and Dean, were successful heterosexual adopters. Their children had already been placed in their care, and they had reportedly settled well with them. Their excerpts reflect their perceptions and experiences after adoption:

The children have attached to us, and we are really, really lucky. We were hugely lucky that they had one attachment with the foster carer. It was good attachment, but they can easily attach to us. We have been really lucky with how the girls have settled and how the process went. We did not have any issues really. [Hillary and Marius]

They are now our children you know. Although we adopted both of them, they have a strong attachment with each other and us. The whole problem with HIV and my cancer is that it prevented me from having my own children but that no longer matters really. They are both our own. [Jenny and Dean]

The above extracts suggest that adoption provides opportunities to create positive attachments with non-biological children, who become ones' own with a personal sense of conquering infertility-facilitated power and control within a new life of adoptive parenthood. In that, the assessment process needed to be good enough:

Even though you are looking after someone else's child, at the end of the day, we knew we had to have a good assessment. It was all worth it because the girls are such a joy. The day the social workers brought them to us, we sat there, and we were so happy, and we thought what do we do to make them so happy? [Hillary and Marius]

For Hillary and Marius, a thorough and sensitive assessment may facilitate positive experiences and success, and furthermore generate satisfaction and happiness for the adoptive child. The claim that it is '*someone else's' child at the end of the day*', suggests that the embodiment of infertility is permanent and remembered even when adoption is successful. Ultimately, adoption is seen as a commitment:

No disrespect to birth parents at all but you know, the commitment and dedication is quite a lot. I think it is because of the fight against challenges involved ... There is an understanding that people like me who have gone for adoption, I think, ... it is quite a

powerful thing when you think about it. That is a lot to be in a thankful position. It is very good. [Alan]

The above excerpt depicts that successfully adopting children provides liberation and a real sense of accomplishment.

In summary, the four themes presented paint a picture of strife and huge emotional struggles for PLWHIV on their journey for adoption, filled with stigma and discrimination and, for some, immense joy on being successful. Adoption can be associated with various experiences, but possible.

Discussion

Our findings expand on what we know of PLWHIV struggling with the systems that control the process of adoption; the experiences highlight their reactions and responses that are linked to infertility and health-related loss. Participants in our study were feeling ready to adopt. Their resilience allowed them to fight through various challenges and tensions associated with the desire to achieve adoptive parenthood while living with HIV, an illness that they did not find readily accepted within the adoption system (van Eeden-Moorefield, 2007).

Congruent with other studies, stigma and discrimination persist within interventions available for PLWHIV to achieve parenthood (Peak, Nowoweiski & Giles, 2012). Unique to this study are findings whereby the disclosure of HIV status during various stages of adoption assessments could result in PLWHIV feeling that they are being denied adoption services, assessments and that they are receiving little support.

Achieving parenthood is dependent on practitioners and decision makers' subjective assessments and creates inconsistency around how adoption assessments are undertaken. This study suggests that differences in adoption practice within different agencies may result in some PLWHIV approaching different agencies and being subjected to high levels of scrutiny but receiving every consideration and assessment outcomes. From participants' perspectives, the adoption assessment is underpinned by complex procedures and legitimate power located within a social, procedural, political and organisational context that may create uncertainty and powerlessness (Underhill et al., 2016). Thus, in many ways, the challenges and stressors PLWHIV experienced would be similar to other prospective adopters. However, PLWHIV continue to be vulnerable to organisational stigma, which could result in oppression and discrimination. Therefore, sensitive strength-based assessments are necessary towards producing positive experiences and outcomes that remain grounded in best interests principles.

Professional insensitivity was associated with frustration, discrimination and was less supported. Nevertheless, positive experiences demonstrate that social workers can provide sensitive adoption services to PLWHIV. While this provides reassurance about the nature of some adoption services, there is a need for universal practice regarding how PLWHIV are assessed. While practices associated with power structures and gatekeeping may be grounded within subjective professional assessments, these may be difficult to combat (Underhill et al. 2016). If adoption social workers acknowledge the structural complexities within which social work practice is placed, then they will be able to share empathy and tolerance in their practice.

Limitations

This is a small qualitative study in a very important subject that has received very little attention from researchers. The findings and implications have strong relevance for the setting in which the study was conducted. Because of the ideographic nature of this IPA study, the findings cannot be generalised to the wider population. However, these results provide particular and detailed individual experiences that allowed the research to become closely connected to aspects of their shared experiences and humanity (Smith, 2004). The study, therefore, provides an understanding of how PLWHIV have lived through and experienced the adoption process in some parts of the UK.

Implications for practice

Based on the literature supporting this study, PLWHIV have a right to parent and a right to adopt. On the other hand, adoption serves to protect vulnerable children. Thus, in regards to best interests principles, this study calls for accessible adoption services. Enhancing awareness of the modern definition of HIV will promote anti-discriminatory and anti-oppressive practices. A framework of *transparency in adoption assessments for PLWHIV and multi-disciplinary training* will raise awareness and remove barriers that sometimes prevent PLWHIV from successfully adopting children. Diagram 1 provides a framework that will help adoption social workers to understand the HIV context with an open mind and a non-discriminatory approach. This framework will support standard government and organisational procedures for assessing prospective adopters. It promotes inclusive practice, best interests principles and parenting suitability, all of which remain pertinent and form the ‘foundation’ for assessments.

Insert Diagram 1 here*

We also recommend the framework developed by the lead author in this paper, Chipawe Cane (2017). Her framework for understanding intersectional stigmas associated with PLWHIV seeking to adopt helps adoption social workers to illuminate intersecting factors affecting PLWHIV at micro, meso, and macro levels as they come through adoption systems. Chipawe Cane's framework encourages social workers to strengthen their approach when working with PLWHIV by applying social work values, principles, rights and cultural competence, as this promotes sensitive practices and creates increased opportunities for those seeking to adopt.

Conclusion

The study provides valuable insight into the experiences of PLWHIV trying to adopt children, demonstrating successful adoptive experiences and practical challenges. Based on PLWHIV's experiences, this study suggests that there are inconsistencies in adoption practices, which may lead to various experiences. These inconsistencies stem from attitudes and unchanged historic views and perceptions about HIV. The research emphasises the need for continuous efforts around inclusive practices and empowering PLWHIV to adopt children if they are considered competent to do so, in the same manner as prospective adopters in the wider population.

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